

CHARTER

SECRETARY'S ADVISORY COMMITTEE ON GENETICS, HEALTH, AND SOCIETY

Purpose

Considering that extraordinary scientific advances in biology and human genetics, including the sequencing of the human genome, are speeding the development of new technologies to prevent, treat, and cure disease; that these technologies also have nonmedical applications in areas such as education, employment and law; and that the technologies have substantial benefits, but also the potential to be applied in ways that can be harmful to individuals or society, the Secretary's Advisory Committee on Genetics, Health, and Society (Committee) is established to: (1) provide a forum for expert discussion and deliberation and the formulation of advice and recommendations on the range of complex and sensitive medical, ethical, legal and social issues raised by new technological developments in human genetics; (2) assist the Department of Health and Human Services and, at their request, other Federal agencies in exploring issues raised by the development and application of genetic technologies; and (3) make recommendations to the Secretary of Health and Human Services (Secretary) concerning how these issues should be addressed.

Authority

42 U.S.C. 217a, section 222 of the Public Health Service (PHS) Act, as amended. The Committee is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C. Appendix 2), which sets forth standards for the formation and use of advisory committees.

Function

The Committee shall explore, analyze and deliberate on the broad range of human health and societal issues raised by the development and use, as well as potential misuse, of genetic technologies and make recommendations to the Secretary, and other entities as appropriate. The scope of the Committee's charge includes assessing how genetic technologies are being integrated into health care and public health; studying the clinical, ethical, legal and societal implications of new medical applications, such as preimplantation genetic diagnosis, and emerging technological approaches to clinical testing; identifying opportunities and gaps in research and data collection efforts; exploring the potential misuse of genetics in bioterrorism; examining current patent policy and licensing practices for their impact on access to genetic

technologies; analyzing uses of genetic information in education, employment, insurance; including health, disability, long-term care, and life, and law, including family, immigration, and forensics; and serving as a public forum for discussion of emerging scientific, ethical, legal and social issues raised by genetic technologies.

The Committee may call upon special consultants, assemble ad hoc working groups, and convene conferences and workshops, as necessary, to assist in the work of the Committee.

Structure

The Committee shall consist of 13 members, including the Chair, appointed by the Secretary, or designee, from authorities knowledgeable about molecular biology, human genetics, health care, public health, bioterrorism, ethics, forensics, law, psychology, social sciences, education, occupational health, insurance, and other relevant fields. Of the appointed members, at least two members shall be specifically selected for their knowledge of consumer issues and concerns and the views and perspectives of the general public.

The following Federal officials, or their designees, shall serve as nonvoting ex officio members of the Committee: Assistant Secretary for Children and Families; Assistant Secretary for Health; Administrator, Agency for Healthcare Research and Quality; Director, Centers for Disease Control and Prevention; Administrator, Centers for Medicare & Medicaid Services; Commissioner of Food and Drugs; Administrator, Health Resources and Services Administration; Director, National Institutes of Health; Director, Office for Civil Rights; Director, Office for Human Research Protections; Attorney General of the United States; Secretary of Commerce; Secretary of Defense; Secretary of Education; Secretary of Energy; Secretary of Labor; Secretary of Veterans Affairs; Chair, Equal Employment Opportunity Commission; Chairman, Federal Trade Commission; and any other officers or employees of the United States, as the Secretary determines are necessary for the Committee to effectively carry out its function.

Members may be invited to serve for overlapping terms of up to four years; terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Members may serve after the expiration of their term until their successors have taken office. A member who has been appointed for a term of four years may not be reappointed to this Committee before two years from the date of expiration of that term of office. Any member appointed to fill a vacancy occurring prior to the expiration of the term for which that member's predecessor was appointed, shall serve for the remainder of that term; persons appointed to complete an unexpired term of less than four years may be reappointed immediately for a full term following completion of the unexpired term.

A quorum for the conduct of business by the full committee shall be a majority of the appointed members. A quorum for each subcommittee shall be three members.

As necessary, standing and ad hoc subcommittees may be established to perform specific functions within the Committee's jurisdiction. The Department Committee Management Officer

will be notified upon establishment of each standing subcommittee and will be given information on its name, membership, function, and estimated frequency of meetings.

Coordination of agenda development and management and operational services shall be provided for the Committee by the Office of Science Policy, Office of the Director, National Institutes of Health.

Meetings

Meetings shall be held not less than two times a year at the call of the Chair, with the advanced approval of a Government official who shall also approve the agenda. A Government official shall be present at all meetings.

Meetings shall be open to the public except as determined otherwise by the Secretary. Notice of all meetings shall be given to the public.

Meetings shall be conducted and records of the proceedings kept, as required by applicable laws and Departmental policies.

Compensation

Members shall be paid at the rate of \$200 per day, plus per diem and travel expenses, as authorized by section 5703, Title 5 U.S.C. as amended, for persons in the Government service employed intermittently. Members who are officers or employees of the United States Government shall not receive compensation for service on the Committee.

Annual Cost Estimate

The estimated annual cost for operating the Committee, including compensation and travel expenses for members, but excluding staff support, is \$332,244. The estimated annual person-years of staff support required is 3.1, at an estimated annual cost of \$297,735.

Reports

In the event a portion of a meeting is closed to the public, an annual report shall be prepared which shall contain, at a minimum, a list of members and their business addresses, the Committee's functions, dates, places of meetings, and a summary of committee activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

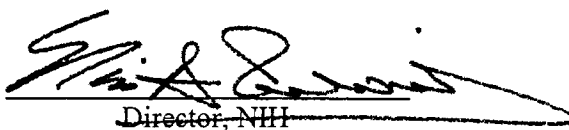
Termination Date

Unless renewed by appropriate action prior to its expiration, the Charter for the Secretary's Advisory Committee on Genetics, Health, and Society will expire on September 23, 2006.

Approved:

JUL 20 2004

Date


Director, NIH